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DOI:

[10.1111/jan.13041](https://doi.org/10.1111/jan.13041)

Document Version

Peer reviewed version

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Citation for published version (APA):

Tuffrey-Wijne, I., Abraham, E., Goulding, L., Giatras, N., Edwards, C., Gillard, S., & Hollins, S. (2016). Role confusion as a barrier to effective carer involvement for people with intellectual disabilities in acute hospitals: findings from a mixed-method study. *Journal of Advanced Nursing*, 72(11), 2907–2922 .
<https://doi.org/10.1111/jan.13041>

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Received Date : 19-Nov-2015

Revised Date : 26-Apr-2016

Accepted Date : 11-May-2016

Article type : Original Research: Empirical research - mixed methods

TITLE PAGE

FULL TITLE

Role confusion as a barrier to effective carer involvement for people with intellectual disabilities in acute hospitals: findings from a mixed-method study

RUNNING HEAD

Carer involvement for people with intellectual disabilities in acute hospitals

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This is an Accepted Article that has been peer-reviewed and approved for publication in the *Journal of Advanced Nursing*, but has yet to undergo copy-editing and proof correction. Please cite this article as an "Accepted Article"; doi: 10.1111/jan.13041
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ACKNOWLEDGEMENTS

The authors are grateful to the anonymous collaborators, staff, patients and carers at the six study sites. This research was undertaken with support from a multi-disciplinary research team and a research advisory board chaired by **Sir Leonard Fenwick**. In particular, we acknowledge the contribution of family carers on the research advisory board, **Monica Stannard** and **Vicki Raphael**, who helped with designing the carer questionnaires and interview guides and discussed emerging findings. Research team members with intellectual disabilities were **Gary Butler** (data collection and analysis) and **Paul Adeline** (data

collection and analysis). Other research team members were Dr **Sarah White** (quantitative analysis and statistical support), and Dr **Sara Christian** (staff questionnaire development).

Acknowledgements for Lucy Goulding:

King's Improvement Science is part of the NIHR CLAHRC South London and comprises a specialist team of improvement scientists and senior researchers based at King's College London. Its work is funded by King's Health Partners (Guy's and St Thomas' NHS Foundation Trust, King's College Hospital NHS Foundation Trust, King's College London and South London and Maudsley NHS Foundation Trust), Guy's and St Thomas' Charity, the Maudsley Charity and the Health Foundation

CONFLICT OF INTEREST STATEMENT

The authors declare that there is no conflict of interest.

FUNDING STATEMENT

This project was funded by the **National Institute for Health Research Health Services and Delivery Research Programme** (project number 10/1007/22). Further information available at: <http://www.netscc.ac.uk/hsdr/projdetails.php?ref=10-1007-22>.

The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the HS&DR programme, NIHR, NHS or the UK Department of Health.

ABSTRACT

Aims: To understand issues around carer roles that affect carer involvement for people with intellectual disabilities in acute hospitals

Background: There is evidence that a lack of effective carer involvement can lead to poorer health outcomes for people with intellectual disabilities, but there is a lack of insight into the reasons for poor carer involvement in acute hospitals.

Design: Mixed methods were used in six acute hospital trusts in England (2011-2013).

Methods: Electronic hospital staff survey (n=990, incl 541 nurses); carer questionnaires (n=88); semi-structured interviews with hospital staff (n=68) and carers (n=37). Data were triangulated and analysed using a conceptual framework based on the literature.

Results: There was strong support for carer involvement among hospital staff, and most carers indicated that they felt welcomed and supported. However, an investigation of negative experiences showed that there were discrepancies in the perspectives of hospital staff and carers on the scope of 'carer involvement'. An important contributory factor to the effectiveness of carer involvement was the degree to which staff understood the importance of carer *expertise* (rather than simply carer *work*) and welcomed it. Carers' contributions to basic nursing care tasks could be taken for granted by hospital staff, sometimes erroneously.

Conclusion: The roles and contributions of carers should be clarified on an individual basis by hospital staff. The authors propose a new model to support this clarification. Further research is needed to assess the suitability of the model, both for patients with intellectual disabilities and for other vulnerable patient groups.

KEY WORDS

Intellectual disabilities, acute hospitals, carer involvement, nursing, patient safety, mixed methods

SUMMARY STATEMENT

Why is this research needed?

- It has been demonstrated that a lack of effective carer involvement for people with intellectual disabilities in healthcare settings can lead to poorer health outcomes, including avoidable deaths.
- UK strategies and guidelines stipulate that carers should be involved as partners in healthcare provision as a matter of course, yet there continue to be reports of poor carer involvement.
- There has been little research into the reasons why acute hospitals do not consistently involve carers of people with intellectual disabilities and take their views into account.

What are the key findings?

- Hospital staff indicated overwhelming support for carer involvement and the majority of carers reported that they felt well supported in their role; however, a significant minority did not.

- Scrutiny of episodes of sub-optimal care or compromised patient safety highlighted that discrepancies in perspective on the role of carers was a common feature of such scenarios.
- Negative experiences included instances where staff wrongly assumed that carers of people with intellectual disabilities would provide basic nursing care, or where carer expertise was not acted upon.

How should the findings be used to influence policy/practice/research/education?

- All hospital staff should be educated not only in the importance of carer involvement for people with intellectual disabilities (and other vulnerable patient groups), but also in its nature and scope.
- We have proposed a new model for clarifying carer involvement which should form the basis of further research. It could become part of future hospital policies and practice.
- Further research is needed to establish the generalisability of findings and the usefulness of the proposed model, both for patients with intellectual disabilities and for other vulnerable patient groups.

MAIN TEXT

INTRODUCTION

Poor health outcomes for people with intellectual disabilities have been a subject of growing international concern (van Schrojenstein Lantman-de-Valk & Noonan Walsh 2008, Haveman *et al.* 2009, O'Hara *et al.* 2010, Emerson & Hatton 2013). In the UK, a number of reports and government inquiries have highlighted widespread poor healthcare provision for patients with intellectual disabilities, leading to compromised patient safety and avoidable deaths (Mencap 2007, Michael 2008, Parliamentary and Health Service Ombudsman 2009, Mencap 2012, Department of Health 2013, Heslop *et al.* 2013). This has led to a range of policies, recommendations and strategies for promoting better and safer healthcare delivery, including the need for carer involvement (Mencap 2010). An independent inquiry into access to healthcare for people with intellectual disabilities in the UK (Michael 2008) recommended that:

Family and other carers should be involved as a matter of course as partners in the provision of treatment and care unless good reason is given, and trust boards should ensure that reasonable adjustments are made to enable and support carers to do this effectively. (p.11)

In some countries the law specifically requires that disabled persons receive reasonable adjustments (Disability Discrimination Act 2005) or accommodations (Americans with Disabilities Act 1990) in order to improve access to a service.

There is evidence that a lack of effective carer involvement can lead to poorer health outcomes for people with intellectual disabilities. A Confidential Inquiry found that failure to take carer views into account was a contributory factor in the premature deaths of people with intellectual disabilities (Heslop *et al.* 2013).

However, whilst the problem is well documented, the reasons why carer views are not taken into account have not been the subject of much research. In this paper we focus on the issue of role confusion as a barrier to effective carer involvement. We draw on research that investigated the challenges hospitals face in implementing the above UK recommendation around carer involvement (Michael 2008). It was part of a larger study funded by the National Institute for Health Research in England. A comprehensive description of the methodology and the full results of that study have been reported elsewhere (Tuffrey-Wijne *et al.*, 2013).

BACKGROUND

Definitions

Around 2% of the population have intellectual disabilities (Emerson & Hatton 2008). People with intellectual disabilities (in the UK also known as ‘learning disabilities’) have ‘a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning) which started before adulthood, with a lasting effect on development’ (Department of Health 2009, p14).

For the purpose of this paper, a ‘carer’ is defined as any care giver who provides paid or unpaid support to a person with intellectual disabilities in the community who could not manage without this help.

A survey of family carers in England in 2012-13 found that 73% of carers of people with intellectual disabilities had been caring for over 20 years; 48% spent over 100 hours a week caring for the person (Hatton *et al.* 2014). Such carers, therefore, often have very high levels of experience and expertise with regards to the person they care for.

Whilst the most common place of residence for people with intellectual disabilities in England is with family or friends, many rely on the support of paid care staff in residential care, independent living arrangements and sheltered accommodation settings (Hatton *et al.* 2014). These are usually social care staff rather than healthcare staff. Their level of training, expertise and knowledge of the client can vary widely.

The experiences of carers in acute hospitals

There have been some small scale qualitative studies which explored the experiences of family and paid carers of hospitalised adults with intellectual disabilities. Carers have described support roles that include providing support with personal care, mealtimes, communication, emotional support and reassurance; providing information about the patient to hospital staff; and advocating for the patient’s needs (Webber *et al.* 2010, Hemsley *et al.* 2011). Reported problems include poor staff attitudes, uncertainty about what the carers can do, not being supported to take a break from caring, fear that the patient’s basic needs would not be met if the carer was absent, and lack of recognition for the carers’ expertise and advocacy role (Hemsley *et al.* 2007, Gibbs *et al.* 2008, Dinsmore 2012).

The work of Allen (Allen 2000) is particularly relevant in understanding conflicting interpretations of the concept of carer involvement. Allen conducted an ethnographic study in a UK hospital, investigating the different degrees to which family carers of any patients (not focused on intellectual disabilities) were involved with patient care. Family members could act as ‘visitors’, undertaking caring activities that are largely taken for granted by nursing staff; ‘workers’, undertaking more intimate care-giving tasks and being of help to the ward staff; or ‘expert carers’, supporting the patient’s highly specific care needs and highlighting the patient’s needs to the ward staff. Allen noted that whilst relatives and friends who adopted a worker role remained subordinate members of the work-force, fitting in with ward routines and hierarchies, expert carers were more oriented to the needs of the patient regardless of the needs of the ward. As a consequence, their actions could lead them to disrupt fundamental features of the organisation of ward work, making their integration into the ward problematic. These issues were incorporated into a conceptual framework that guided the focused analysis of carer-related data (Figure 1).

THE STUDY

Aims and objectives

The study aims were to identify the factors that affect carer involvement for people with intellectual disabilities in acute hospitals and to develop guidance to promote effective carer involvement. The research questions were:

1. What systems and structural changes have been put in place in acute hospitals to support carer involvement, and how effective are these?
2. What are the organisational and individual barriers and enablers to effective carer involvement?
3. What are perspectives and experiences of carers and hospital staff in relation to carer involvement?

Design and setting

A mixed methods design was employed, which is particularly suited to meeting practical needs for assessing and understanding the complexities of health service delivery (Miller *et al.* 2013). The study was carried out across six acute National Health Service (NHS) trusts in England (see Table 1) and lasted 21 months (2011-2013).

Participants

Each site had a study collaborator (the director of nursing or a hospital-based intellectual disability liaison nurse) who promoted the study within their hospital and facilitated participant recruitment.

Investigating formal systems: A strategic hospital manager at each site was asked to provide information about the hospital's carer-related policies, structures and systems.

Staff interviews: Semi-structured interviews were conducted with purposively selected staff, as follows: the medical director, director of nursing and one other strategic manager; the ward

manager and two nurses from two or three wards per hospital (including a medical assessment unit and a ward which had relatively high numbers of patients with intellectual disabilities); and any other staff members who had relevant experiences or specific responsibilities for implementing intellectual disability policies.

Staff questionnaires: The link to an electronic staff survey was emailed by a strategic hospital manager to all clinical staff within the hospital.

Carer questionnaires: Inclusion criteria for carers required being a family or paid carer of an adult with intellectual disabilities admitted to the hospital during a 12 month study period. Potential participants were given or sent a paper questionnaire, usually by the hospital's intellectual disability liaison nurse (IDLN).

Carer interviews: A self-selected sample of survey respondents were interviewed, either in person or by telephone. In addition, people with intellectual disabilities were invited to attend open days at the hospital (this part of the study is not reported here); carers accompanying the attendees were invited to participate in a face-to-face interview.

Data collection

The interview schedules and survey questions were based on a research framework for the overall study which took account of the wider literature (for full details, see Tuffrey-Wijne *et al.*, 2013; Table 2 lists the carer-related questions within the research framework). Initial analysis of the earliest staff interviews was used to further develop the staff survey questions. Family carers who were members of the Research Advisory Group took part in meetings to develop the carer survey.

Respondents to the staff questionnaire were asked to indicate on a Likert-type scale to what extent they agreed with carer-related statements. Questions were included on the availability of carer support within their work settings, as well as their views on carer involvement. The interview schedule for ward staff included a fictional scenario involving a patient with intellectual disabilities accompanied to the ward by his brother; this was designed to assess staff views and knowledge of policies, procedures, structures and issues related to learning disability and carer involvement. The interview guide also included the question: “What are your personal views, ideas and opinions about including family and carers as partners in care?”

The carer survey included Likert-type questions about the extent to which carers had been involved, consulted and supported in their role as carer. In the interviews, carers were asked to expand on their responses to the carer survey (if completed) and to reflect on their most recent experience as carer of a person with intellectual disabilities in hospital.

Interviews lasted between 30 and 60 minutes. They were audio-recorded, with the exception of some carer interviews. Audio-recordings were transcribed verbatim. Non-audio-recorded interviews were described by the researcher immediately afterwards; these descriptions were sent to the interviewee for verification and approval.

Data analysis

Qualitative data were analysed using Nvivo 9 (Bazeley & Jackson 2013). Coding and data analysis took place throughout the data collection period and involved weekly research team discussions. New inductive codes were adopted where data did not fit into the initial coding

framework and themes were subsequently developed. Questionnaire data were entered into SPSS Statistics 19 and analysed using descriptive statistics.

In analysing the ‘fit’ of the data, particular attention was paid to areas of discordance between different data sets, both across participant groups (e.g. a lack of coherence between staff data and carer data) and within participant groups (e.g. a lack of coherence between staff questionnaires and staff interviews). Triangulation of qualitative and quantitative data helped to explain and understand the issues around carer involvement. To support this process, the research team looked for expansion of the phenomenon ‘carer involvement’ and conducted a further literature search on ‘carer roles’ in order to seek explanations from theory on the discordant findings (Fetters *et al.* 2013).

Validity and reliability

The involvement of six diverse participating hospitals trusts and triangulation of diverse data sets enhanced validity of the findings. Reliability was increased through monthly meetings with the wider research team and ad-hoc meetings with specific stakeholders on the research advisory board (including family carers) to discuss emerging findings. In order to test validity and reliability further, the findings and preliminary conclusions were presented to and discussed with ‘expert panels’ consisting of a total of 42 managers and other staff at four participating hospital sites (see Table 3 for the expert panel discussion paper relating to carer involvement).

Ethical approvals

The study was approved by the National Research Ethics Services (NRES). Local research approvals were obtained at each participating trust.

RESULTS

The key findings in relation to the research questions are summarised in table 3.

Participants

Sixty-eight staff interviews and 37 carer interviews were conducted. Usable questionnaires were completed by 990 staff and 88 carers (see table 4).

Carer policies

Two hospital trusts had formal policies to support carers, and three were in the process of developing and implementing such policies. These typically included the need to provide practical support, such as the provision of food and drink or facilities to stay with the patient. Interview data showed that there was a good understanding among directors of nursing and medical directors of the need for carer involvement and strong support for welcoming carers as partners in care. Ward nurses were not always aware of carer policies, but mostly understood the requirement to provide extra facilities for carers.

Staff and carer surveys

Figure 2 shows the extent to which staff agreed or disagreed with statements relating to carer involvement. It can be seen that there was strong staff support for carer involvement, with 89% of respondents stating that it was standard practice in their clinical area to involve family and carers. 93% of staff agreed that carers help provide practical support, and even higher proportions agreed that carers help with the patient's communication, emotional needs and reassurance. However, over half of staff agreed that supporting carers was time consuming, and 30% thought that carers could interfere.

Figure 3 shows the level of agreement among carers with statements related to their most recent experience of supporting someone with intellectual disabilities in hospital. Most carers (85%) indicated that staff were welcoming and supportive of them as carers; 77% said they were recognised as the expert carer and listened to, and 77% said that they were fully consulted and listened to before decisions were taken about the person's treatment and care. However, this left a significant minority of carers who were dissatisfied on some items.

Carer roles

The hospital staff and carer interviewees described a wide range of roles for carers of people with intellectual disabilities in hospital (table 5). The data are presented using Allen's distinction between 'visitor', 'worker' and 'expert' roles (figure 1).

Carers as ‘visitors’

There was wide consensus among nurses that carers were welcomed on their wards and were offered practical support, in particular food and drink, unlimited visiting hours and facilities to stay with the patient. However, despite this positive staff attitude and the supportive carer policies that were in place in some hospitals, over a third of interviewed carers said that such provisions were absent or haphazard;

Interviewer: Do your staff usually get tea or coffee, for example?

Paid carer: It depends on the ward! We can’t rely on it. We always go prepared! It’s a long day otherwise, from 8 to 8.

Family carer: She [*mother*] stayed here for a week and didn’t get any bed, wasn’t even offered breakfast.

These interviewees were, in effect, treated as ‘visitors’ rather than ‘workers’ who needed support in their caring role. This was evident in reports of hands-on, involved ‘worker’ carers who were asked to leave at the end of visiting hours.

Carers as ‘workers’

Feeling unsupported in their role as carers stemmed not only from a lack of access to facilities, but also from an over-reliance on carers with too few opportunities to have a break from caring. It seemed that for patients with intellectual disabilities, carers’ ‘worker’ roles were often taken for granted, leaving carers unsupported, exhausted or even scared;

Family carer: There’s just, “Can you do it?” and they [*nurses*] left. No-one completed a conversation with me. I didn’t have the opportunity to say, “Well I can’t, I’m on my way out.” No-one said, “Well I’ll come and do something about it.” There was no communication there.

Paid carer: Hospital staff always assume that carers will do all personal care and there is no conversation or agreement about what carers will do and what hospital staff will do... For example, when one of our clients is in recovery after an operation, the staff will call us to be with them. This can be a little frightening as it is an unfamiliar environment... We are not asked whether we feel OK about supporting the patient in these situations.

Carers as 'experts'

Whilst the carer survey data showed high levels of recognition of carer expertise, there was nonetheless a significant minority of carers experiencing the reverse, sometimes with serious consequences. Reports of compromised patient care came mostly from carer interviews but were also reported by staff, particularly in hindsight;

Senior strategic manager: Despite what appeared to be quite close medical and nursing scrutiny, deterioration wasn't picked up... The patient then got very unwell... Afterwards the mother said, "I know my daughter and *told* them she was deteriorating". Clearly in retrospect she was right.

Family carer: In the endoscopy, I always take him in and I'll say "He doesn't like being on his back – flat. 'Cos he might choke – really can choke", and then when he came out, the doctor came up to us, and says, "You were right you know, he doesn't like being on his back 'cos we laid him flat going on his back and he panicked." And I say, "Well I know". But you see, they don't listen to his parents.'

Discrepancies between staff and carer understanding of the carer role

During the qualitative analysis new categories emerged which highlighted negative experiences of carer involvement ('Carer ignored'; 'Carer can't do some nursing tasks'; 'Reliance on carer'; 'Tension between carer and ward staff'). Overall, staff and carers conceptualised the role of the carer differently.

Hospital staff mostly spoke about the importance of carer as ‘workers’ who could help in reducing the patient’s anxiety, calm the patient down, and help with basic nursing care. Many carers, on the other hand, talked about the importance of sharing their expert knowledge of the patient with staff; there were particular concerns if such expertise was not acted on;

Family carer: I felt I couldn’t leave him. I stayed with him from 8am to 7pm every day, because the nurses were so clueless.

Scrutiny of episodes of sub-optimal care or compromised patient safety highlighted that a lack of clarity about the nature of carer involvement was a common feature of such scenarios. For example, in one instance a patient with intellectual disabilities started to develop a pressure sore whilst in hospital, as the nurses had wrongly assumed that the paid carers would provide basic nursing care (including pressure area care) and had not checked this.

Role confusion was a particular risk if paid social care staff was involved, whose job was poorly understood by hospital nurses. The following (unrelated) quotes exemplify this;

Paid carer: *[The hospital nurses]* expected us to do things that we shouldn’t really be doing. They asked us to help with toileting, but... we never help our clients with toileting... *[The nurses]* asked our support workers to go in for some quite intimate procedures, like helping with a groin wound: “Could you just come in and hold this or push this?” Now that could be really awkward... It blurs the boundaries of your relationship with the client... So we give our staff quite clear boundaries about what they shouldn’t be doing. But they are made to feel uncomfortable on the ward if they are asked to assist and they say no.

Senior staff nurse: If they are a live-in carer or full-time carer of that patient, then they should be fully involved in caring... here in hospital as well... I don’t think it’s any use to me or the patient for them just to be sat there... Why would you just need somebody to sit there in a chair, you know, not being involved in feeding?

Further examples of the different and conflicting ways in which carer involvement was interpreted are given in Table 6.

Conversely, where the role of carers as experts was well understood and supported, with carers' concerns listened to and acted upon, reported outcomes were good and carer satisfaction was high;

Family carer: The nurses were very attentive and they called me in the morning before I came on the ward... They said, "[*Your daughter*] seems quite sleepy" and I said "Unfortunately that's her condition". They could see how drowsy [*my daughter*] was so they were quite concerned and asked for my advice, which was fine. It gives me confidence thinking, "They're watching her, they're looking after her until I come onto the ward."

A new model for effective carer involvement

The triangulated data from the surveys and interviews show that whilst there was strong support among ward staff for the concept of 'carer involvement', in practice carer involvement was patchy. Hospital policies were focused on offering carers practical support. Such policies were enabling, as without practical support it was difficult for carers to contribute. They did not, however, guarantee effective carer involvement. The combined interview responses show clear tensions between carers and hospital staff, which often arose simply because there was a lack of clarity about mutual roles. Some senior managers were aware of this tension, and in one hospital trust, a 'protocol for shared care' was being trialled after the data collection period;

Senior hospital manager: We now have as part of our carers policy, a kind of negotiation that we have with the carers that says, 'Okay, Joe's in here, you normally do all of these things, while he's in hospital what of those do you want to carry on doing, and what of those do you want us to take up?' (...) We need to make sure we've documented that and we reflect on how that changes.

The data pointed to a clear need to agree and document on ward/clinic level to what degree families and other carers (including paid care staff) are involved in supporting a patient with intellectual disabilities in hospital. This led us to propose a new model for clarifying carer involvement (Figure 4). It incorporates not only (a) the degree carers are 'workers' who will contribute to the provision of basic nursing care (as, for example, referred to by the senior hospital manager in the above quote), but also (b) the degree to which carers are experts or non-experts. Making these two aspects of carer roles explicit may help staff to understand the particular contributions of carers, and thus avoid tensions. For example, the presence of paid care staff may be required to help the patient cope with an unfamiliar environment, but these carers may be unable to contribute to certain nursing care tasks that are outside their remit (as in some of the quotes above); such carers would score "high" on expertise and on emotional support tasks, but "low" on physical support tasks. The model would also identify carers who lack expertise about the patient; several interviewees reported frustration with social care staff accompanying clients with intellectual disabilities into hospital, who were agency staff unfamiliar with the patient, and therefore could not provide specific information about the needs of that patient.

For each patient with intellectual disabilities, it should be established whether there is carer expertise available; if so, such expertise should be sought and utilised even if the carer is not physically present on the ward. This includes keeping carers informed, seeking their knowledge of the patient, taking their advice into account and involving them in planning treatment and care. In terms of carer involvement in the 'work' of caring, carers in this study

reported a lack of communication and agreement with hospital staff. The levels of carer involvement in basic nursing care tasks, communication support and reassurance, through the carers' presence with the patient in hospital, should not be assumed but needs to be clarified. As carer involvement may change during the hospital admission, this should be reviewed regularly.

DISCUSSION

This paper presents a focused investigation of how staff and carer understanding of the carer role might affect carer involvement for patients with intellectual disabilities in acute hospitals. The survey data indicate very high staff awareness of good practice. Carer satisfaction with the way they were treated was generally good. However, a significant minority of carers were dissatisfied on some items. These findings suggest that whilst most staff are aware that carer involvement is important, they may not always be able to facilitate it. The qualitative interview data enabled in-depth exploration of the issues.

The study found that an important contributory factor to the effectiveness of carer involvement was the degree to which staff understood the importance of carer *expertise* (rather than simply carer *work*) and welcomed it, and the degree to which the roles of both staff and carers were clarified on an individual basis. We found examples across all study sites of misunderstanding of and resistance to involving carer expertise. Discrepancies in perspective on the carer role and the scope of 'carer involvement' went some way in explaining why there continued to be instances of a lack of effective carer involvement leading to compromised patient safety. Our conceptual framework for data analysis (figure 1) proved a useful starting point and was a good fit with the data.

There are particular challenges for negotiating carer roles for patients with intellectual disabilities. There is a certain degree of overlap between ‘visitor’, ‘worker’ and ‘expert’ carer roles for all patients, but these overlaps were significant for patients with intellectual disabilities. For example, providing basic comfort or keeping a watchful eye on the patient’s safety may be seen as visitor roles for the general population: useful and welcome, but dispensable. For a patient with intellectual disabilities these roles may not only require intimate knowledge of the patient and the way he or she copes with an unfamiliar hospital environment; they may also be indispensable to ward nurses, as some patients’ behaviour (especially when they are anxious) may be detrimental to the patient’s wellbeing and disturbing to ward routines. Such roles should therefore not be taken for granted in the way visitor roles are, but rather, they require a hospital’s support for carers. They could be seen as ‘expert’ roles, which are indispensable to nurses and particularly important with regards to high quality care and patient safety.

Paid carers were at particular risk of role misunderstandings, as hospital staff could be very unclear about paid carers’ levels of involvement in care tasks and levels of expert knowledge about the patient. Ward nurses often assumed that paid carers were health workers like themselves and left caring tasks to paid carers who could be ill-equipped (or even forbidden by their managers) to perform them. At best, these misunderstandings and variations could cause resentment and to confusion for the patient; at worst, it could lead to compromised safety.

The findings above identify the expertise of carers and their willingness to participate in patient care in hospital settings as key factors in effective carer involvement. However, it also shows the diversity of carers in terms of their capabilities and desire for involvement, and suggests that awareness and accurate assessment of these two dimensions could improve

relationships with carers and better utilisation of their skills. Figure 4 presents a model for clarifying carer expertise and involvement. It draws attention to the need to assess both expertise and desire for involvement and the way in which these may vary from carer. However, while these guidelines have the potential to facilitate carer involvement our research also reveals significant barriers which could impede their use.

In the current economic climate of funding cuts and increased pressures on staff, it is worth highlighting that over half of all staff survey respondents indicated that supporting carers is time consuming. Tensions around carer roles might be addressed through a combination of training, policies and supportive structures, but a lack of staff time to support carers and patients will almost certainly impede good practice.

Good communication between hospital staff and carers is key to building mutual understanding and trust, which is an important starting point for effective carer involvement. This echoes findings from studies on carers of people with dementia (Jurgens *et al.* 2012, Clissett *et al.* 2013), although little is known about role confusion in relation to carers for other vulnerable patient groups. Therefore, the extent to which the findings of our study, and in particular the proposed new model for clarifying carer involvement, can be generalised to other patient populations will need further investigation.

Strengths and limitations

The ability of hospital staff to identify a population of patients with intellectual disabilities was problematic at all study sites (Tuffrey-Wijne *et al.*, 2013), negatively affecting the recruitment of carers as study participants.

The sampling strategy is a source of selection bias. As the principle method for carer questionnaire distribution was through the IDLN, it is probable that respondents were more likely to be carers who had received input from the IDLN, which may have impacted positively on their hospital experience. Furthermore, there is the strong possibility of response bias, as those carers who hold particularly strong views on the care received (whether positive or negative) may be more likely to respond.

The study identified 'role confusion' as an important contributing factor to a lack of effective carer involvement. However, the extent of the problem has not been quantified. The qualitative data picked up examples of poor practice, but it cannot be said with any certainty how representative these were.

The input from the multi-disciplinary and multi-stakeholder research team and research advisory board (including carers and people with intellectual disabilities) was important in understanding the issues involved, and is a strength of this study.

CONCLUSION

This study provides evidence that a lack of understanding or clarity about carer roles can lead to poorer carer satisfaction and may lead to poorer patient outcomes. This paper presents empirical support for a theoretical model that distinguishes between 'visitor', 'worker' and 'expert' aspects of the carer role with regards to people with intellectual disabilities. The importance and benefits of carer involvement should be part of both pre- and post-registration nurse training; our proposed new model for clarifying carer involvement could guide such training. The model could also aid further development of carer policies in acute hospitals, by making it explicit that the nature and degree of individual carer involvement should be

established and documented. However, it is currently a theoretical model that needs testing, validating and refining. Further research should address the following questions:

- *What is the validity of this theoretical model?*
- *How can the model be used in practice?* Translation of the model into practical applications (including documentation guidance) is needed, before it can be tested. Action research methods would be particularly suited to investigating ways in which carer involvement can be improved.
- *How relevant is this model for other groups of patients and carers, such as those with physical disabilities, dementia or mental health problems?* We believe that the model would work equally well for other carer groups, in other care settings and indeed in other countries, but this will need to be tested.

The support needs of people with intellectual disabilities are huge and complex. Hospitals that can get it right for this group of patients are likely to be able to get it right for all their patients, including those from other vulnerable groups. As such, the care and support hospitals provide for patients with intellectual disabilities and their carers could serve as a benchmark that will benefit all patients.

Author Contributions:

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE*):

- 1) substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- 2) drafting the article or revising it critically for important intellectual content.

* <http://www.icmje.org/recommendations/>

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TABLE 1: Description of participating NHS hospital trusts

Hospital	Type	Area	Access to intellectual disability expertise
A	Teaching	Urban	Hospital-based Intellectual Disability Liaison Nurse (IDLN)
B	District general	Urban	Community-based IDLN
C	District general	Urban	None
D	District general	Urban/rural	Hospital-based IDLN
E	Teaching	Urban/rural	Hospital-based IDLN
F	District general	Rural	Community-based IDLN

TABLE 2: Questions within the research framework related to involving carers of people with intellectual disabilities as partners in care

Organisational context	Staff perspectives: individuals and teams	Carer perspectives
<ul style="list-style-type: none"> • What policies and reasonable adjustments are in place to enable and support family/carers to be involved as effective partners in care provision? • Does the hospital have guidelines on the provision of information for carers, practical support and service co-ordination? • Is there a culture among senior managers that encourages partnerships with family/carers? 	<ul style="list-style-type: none"> • Are staff on hospital wards aware of any policies or the need to make reasonable adjustments to enable and support family/carers to be involved as effective partners in care provision, including care and discharge planning? • In what ways are family/carers involved as partners in care provision by staff on hospital wards? (is there: provision of information, practical support and service co-ordination?) • Is there a culture among staff on hospital wards that encourages partnerships with family/carers? 	<ul style="list-style-type: none"> • Do family/carers feel that they have been supported and included as partners in care provision, including care and discharge planning? • Have family/carers been provided with information and practical support? • Are family/carers satisfied with the care provided by the hospital?

TABLE 3: Key findings and preliminary conclusions, presented and discussed at “Expert Panels” at participating hospital sites

Involving carers are partners in care		
<p>“Family and other carers should be involved as a matter of course as partners in provision of treatment and care, unless a good reason is given. Trust boards should ensure that reasonable adjustments are made to enable and support carers to do this effectively.” Healthcare for All, recommendation 3 (Michael 2008)</p>		
FINDINGS	ISSUES	DISCUSSION POINTS
<p>Importance</p> <p>The vast majority of staff report that carer involvement is very important. Benefits reported: <i>Practical help; Calms the patient; Help with communication.</i> Most staff acknowledge that the carer knows best.</p> <p>Many examples of excellent practice, but this is haphazard.</p> <p>It can vary between sites, between wards, and even between individual staff in the same teams. Wards with higher patient/nurse ratios and wards that are used to involving relatives (eg ITU, paediatrics) are much better evaluated by carers than busy wards with fast patient turnovers (eg A&E, MAU).</p> <p>Ward manager and ward culture can have a huge positive influence. Carers mention ‘good’ wards and ‘bad’ wards.</p> <p>Lack of protocols or agreements for shared care can lead to misunderstanding and, at worst, patient safety risks. There is a lack of understanding and agreement between staff and carers about mutual roles and responsibilities. Many staff interpret “carer involvement” in a limited way: “Getting the carer to agree and cooperate with my plan of care.”</p> <p>Funding for paid carers can be an issue. Sometimes the hospital will pay for this or arrange ‘back fill’ at a residential home but it is unclear under what circumstances this may happen. On other occasions a residential home will simply send (and pay for) a member of care staff to accompany the patient.</p>	<p>Policy on supporting carers (filtered down to ward level), eg provision of refreshments/meals or free parking, is not implemented consistently. This often depends on individual staff.</p> <p>Tensions can arise between hospital staff and carers.</p> <p>These are usually formed when expectations are not mutual and there is disparity between what each group expects and what the other group actually does.</p> <p><i>Eg: Some staff do not understand that it may be inappropriate for some carers to be involved in personal care as they do not perform this function when the patient is at home.</i></p> <p>Family carers are generally viewed in higher regard than paid carers.</p> <p>Problems reported by carers face include:</p> <ul style="list-style-type: none"> not been listened to and recognised as the expert carer being worn out and needing respite being afraid of the clinical environment being relied upon by hospital staff and feeling as if they cannot leave the patient; hospital staff failing to cover for care staff over short breaks. 	<ul style="list-style-type: none"> Do these findings resonate with you? Are the issues around carers same for other vulnerable groups? In particular: how is shared care negotiated (if at all) for carers of people with learning disabilities and those of other vulnerable groups, in particular patients with dementia? Do our recommendations for protocols for shared care seem valid, and could they be non-learning-disability-specific??
<p>PRELIMINARY CONCLUSIONS</p> <ul style="list-style-type: none"> There is strong evidence to suggest that involving carers as experts has a considerable positive effect on patient/carer experience, and may positively affect patient outcomes There is an urgent need for clear protocols for shared care and carer support that are well known and adhered to by clinical staff. 		

TABLE 4: Breakdown of participants

Data collection method	Number of participants
Staff survey	990
Physicians	159
Nurses	541
Health care assistants	83
Allied health professionals	159
Other	48
Not specified	28
Excluded	-28
Staff Interviews	68
Senior managers	18
Ward manager, matron, senior sister, senior nurse	22
Staff nurses	9
Physicians	5
Intellectual Disability Liaison Nurses	6
Community Intellectual Disability Nurses	2
Other	6
Carer survey	88
Family carers	40
Paid carers	54
Excluded	-6
Carer interviews	37
Family carers	19
Paid carers	18

TABLE 5: Summary of carer tasks and roles described by study participants

Carer role	Description/explanation
a) Reassuring the patient	Many people with intellectual disabilities have difficulties in coping with unfamiliar environments or procedures. The presence of a familiar carer often helped patients to cope with the hospital environment.
b) Preventing ward disturbance	Staff and carers mentioned that some patients with intellectual disabilities coped better if they had someone with them who could keep them 'occupied'. Without carer support, managing unconventional or challenging behaviour that could be disturbing to the ward and other patients could be difficult for staff.
c) Giving basic (nursing) care	Many carers supported the nurses' tasks by assisting the patient with washing, dressing, feeding and toileting. These tasks could be time consuming. Some patients with multiple disabilities needed one-to-one (or two-to-one) support with basic nursing care when they were at home. In some cases, carers also offered to assist with the administration of medication.
d) Providing communication support	Carers of patients who had communication difficulties acted as a 'bridge' between the patient and the hospital staff. They could interpret the patient's communication and help hospital staff understand it, and they could 'translate' hospital staff's communication and information about what was happening in a way the patient could understand and cope with. Doctors and nurses found communication support from carers invaluable in their assessment of the patient's needs.
e) Keeping the patient safe	The role of the carer as someone who ensures that the patient is kept safe was described by a number of carers who felt that without their constant presence, the patient would be left anxious, poorly supported, lacking in basic nursing care and even at risk of harm.
f) Contributing expert knowledge	Carers had in-depth knowledge of the patient and his/her needs and could therefore advise and support staff in their attempt to understand the patient's needs. This was important in providing timely treatment and care. Carers' expert knowledge also meant that they could advise staff on the provision of providing appropriately adjusted care. This could include changes to usual procedures or routines.
g) Participating in decision making	Participating in decision making around care, treatment and discharge planning goes beyond simply being informed by hospital staff. It includes being involved in making decisions about appropriate, adjusted treatment and care.

Table 6: Discrepancies in understanding of the carer role: examples

Discrepancy	Examples
Carers viewed themselves as 'experts' and wished to contribute their expert knowledge, whilst staff viewed them as 'workers' who could provide all basic nursing care.	A patient with severe intellectual disabilities, autism and challenging behaviour was accompanied to an emergency hospital admission by several members of his care staff team, who felt that without their support he would not cope with the hospital environment. They felt that they were left by the ward staff to do all the nursing tasks themselves, including some that were beyond their skills. The nurses did not take note of their concerns and suggestions (for example, his need for a side room as he was likely to be noisy and interfere with other patients' equipment).
Carers wished to be seen as 'workers' whereas staff viewed them as 'visitors'.	The parents of a man who was in hospital for several weeks were not offered any food or drink. They felt that the patient needed one of his parents to support him 24/7 but found it difficult to afford meals and refreshments from the hospital canteen.
Staff thought the carers were experts, whereas the carers' expectations were to be 'workers'.	Short term paid carers, including agency care workers, had little or no expert knowledge of the patient yet were expected to be able to provide expertise (for example, on patient assessment).
Staff thought the carers were 'workers' in the sense of being able to assist with basic nursing care or even expert nursing care, whilst the carers were unable to do this.	<p>A brother was asked by a ward nurse to feed the patient, but he had to leave; the nurse did not check this.</p> <p>A hospital nurse needed to obtain the blood sugar levels of a patient with intellectual disabilities who had high support needs. She handed the needle to a paid care staff member who had come in with him; however, this staff member had no training or experience in performing such nursing tasks (she did it anyway).</p>

FIGURE 1: Conceptual framework of carer involvement and carer roles in hospital
based on Allen (2000)

Carers as 'visitors'	Carers as 'workers'	Carers as 'experts'
<ul style="list-style-type: none"> • <i>Taken-for-granted activities, part of normal affective relations between friends</i> • Tidying the bedside area • Pouring drinks • Basic 'comfort work' • Rearranging pillows • Making the patient's needs known to ward staff • Accompanying the patient off the ward • Providing a watchful eye on the patient's safety • Providing recreational activities 	<ul style="list-style-type: none"> • <i>Going beyond taken-for-granted ward activities</i> • <i>Fitting in with ward organisation</i> • <i>Helpful to nurses</i> • Undertaking certain technical procedures • Intimate tending and body products work 	<ul style="list-style-type: none"> • <i>Going beyond taken-for-granted ward activities</i> • <i>Focused on patient rather than nurse</i> • <i>Could disrupt ward organisation</i> • Caring tasks based on 'knowing the patient' • Using expert skills learned through caring at home • Giving and expecting high standards of care

FIGURE 2: Staff views on carer involvement (in percentages)

Source: Staff Survey (questions 6 and 12: n=914; all other questions: n=875)

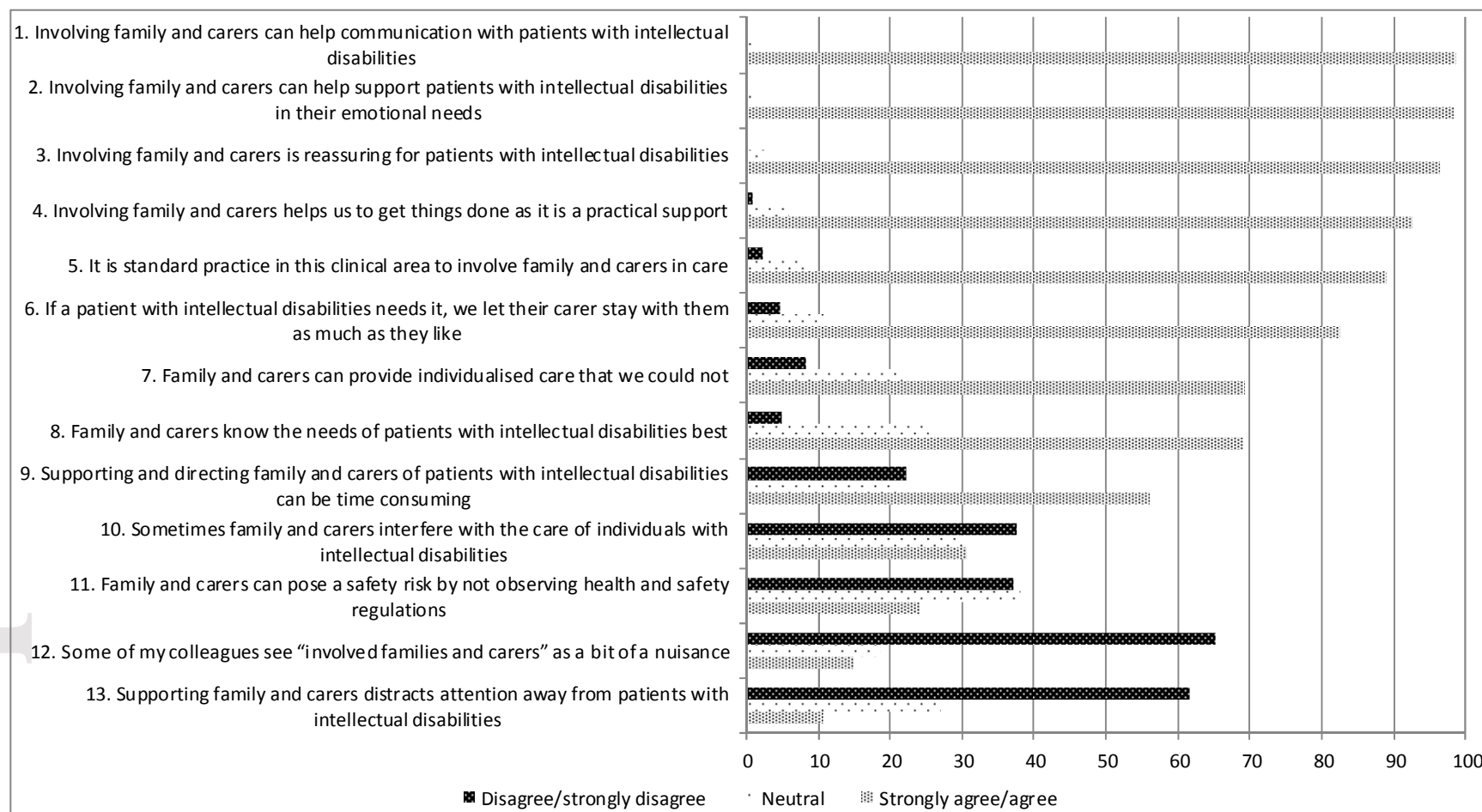


FIGURE 3: Carer feedback on the hospital experience (in percentages)

Source: Carer Survey (n=88)

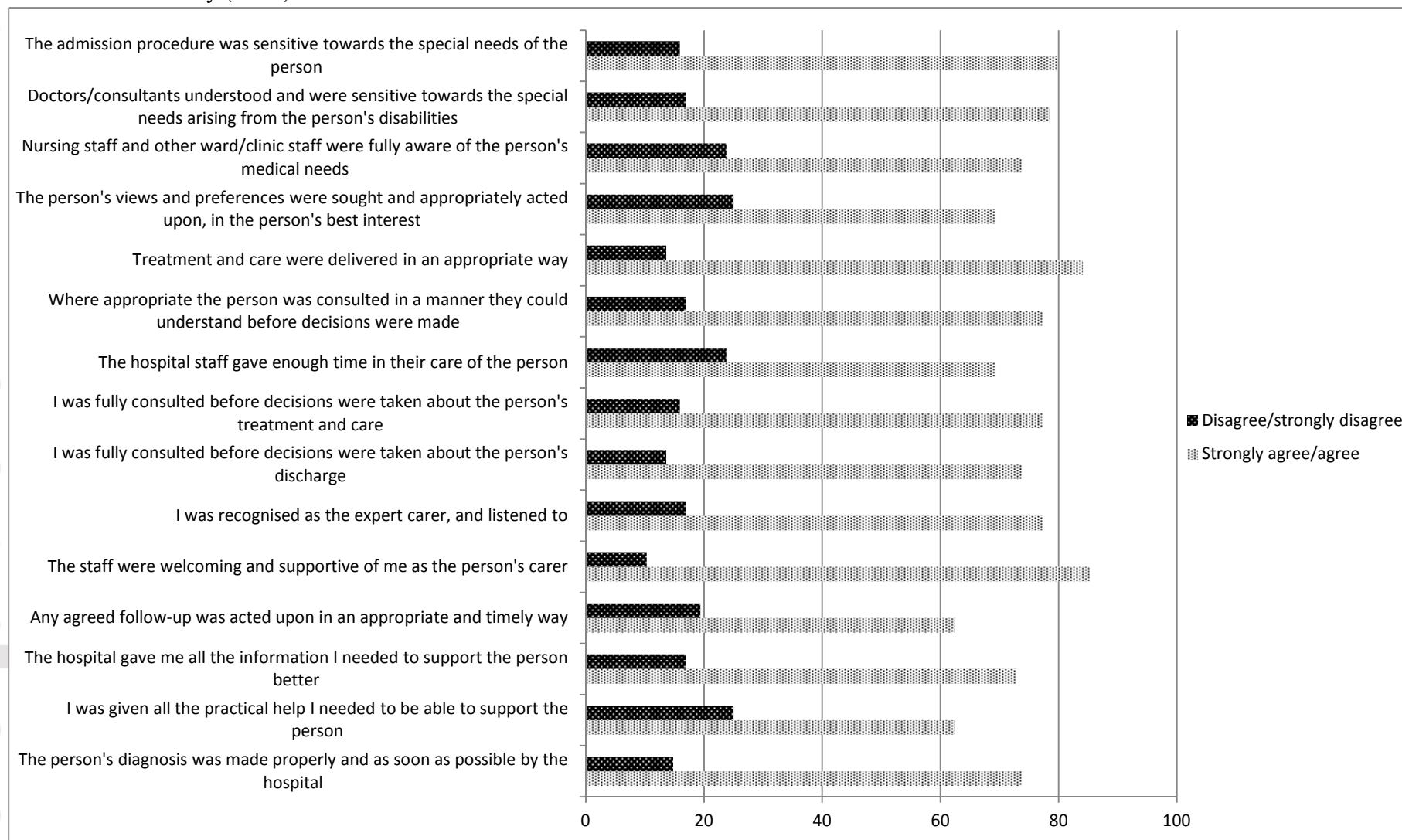
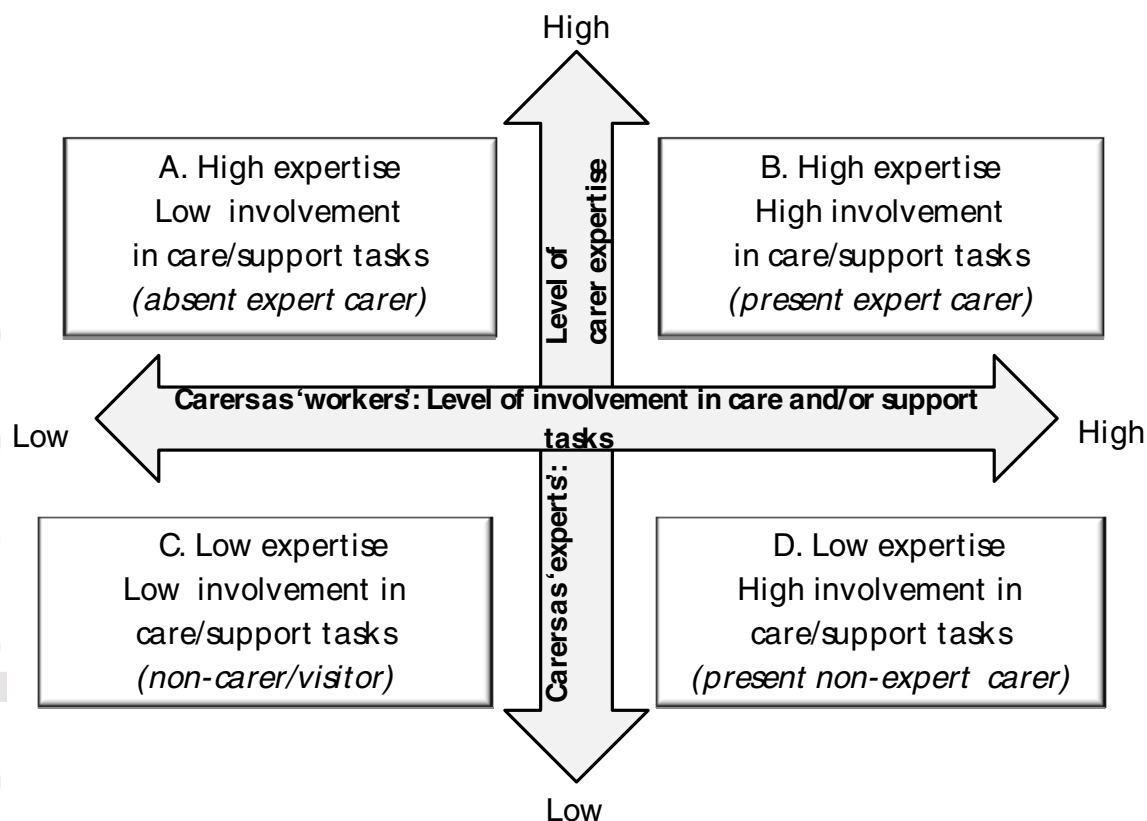


FIGURE 4: Model for clarifying carer involvement and expertise



Protocol for shared care
 Establish each carer's type and level of involvement in care and other tasks

High expertise (A or B):
 Always involve the carer as a partner in care (inform, listen, consult, take carer's views into account)

High involvement in care/support tasks (B or D):
 Agree exact involvement with carer

Review regularly